



Presentation to the Legislative Black Caucus of
Maryland
November 12, 2021

Sickle Cell Disease

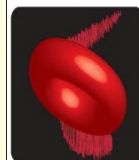
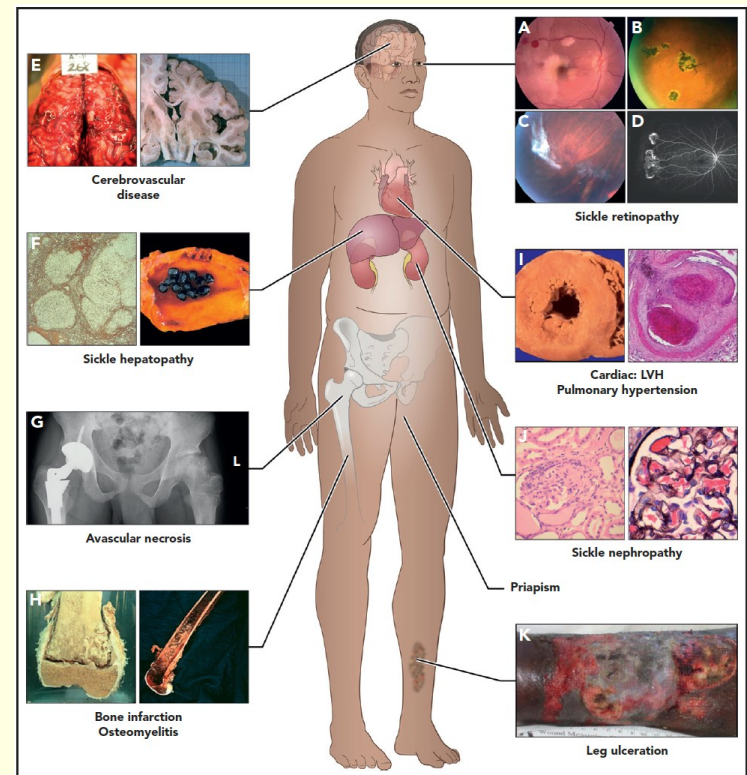
- Affects people of all different racial and ethnic backgrounds, including Africans, Arabian, Israeli, Greek, Italian, Turkish, Indian, Pakistani and Latinos.
- In the US, most common in African Americans and others of African descent.
- Latinos are fastest growing SCD pop in US

Symptoms of SCD

List of Complications

- Pain Crises
- Acute Chest Syndrome
- Anemia
- Infections
- Priapism
- Stroke- overt and silent
- Bone Infarction
- Splenic Sequestration
- Leg Ulcers
- Gallstones
- Growth/Puberty Delay
- Vision/Eye Problems
- Swelling of Hands and Feet

SCD Affects the ENTIRE body
(Image from C. Fitzhugh, MD – NIH)



MSCDA
The Maryland Sickle Cell Disease Association, Inc.
Awareness. Knowledge. Cure.

Overview of SCD in Maryland

- Approx. 5,000 in MD
- About 100 babies are born with the disease each year. Nat'l Cap Area, Balt., E/Shore
- 3,500 Trait
- FY '14: 3,418 Adult hosp costing \$52million (23% Readmissions); 604 Peds Hosp costing \$7million (19% Readmissions); 50% M'aid.

Our Young Adults Continue to Die

- Children are living into adulthood
- Our adults continue to die young.
- In a 2013 study, Dr. Sophie Lanzkron, Dir of the adult SC Center at Johns Hopkins showed that between 1979 -2005, while Peds Mortality declined, adult mortality increased
- Dr. Courtney Fitzhugh, MD (NIH) found the median age with SCD to be 46 in 2015

Barriers to SCD Adult Care

- Lack of Care in Prince George's County: patients forced to travel to Baltimore or Washington, DC
- In FY'19, 57% of hospitalized SCD patients living in PGC were in hospitals outside of PGC
- Lack of education among providers: patients stigmatized and mistreated
- Lack of CHWs to provide social services support

What You Have Done

- 2018 - SB 161: School Management Guidelines. Being rolled out now

**MARYLAND STATE SCHOOL HEALTH SERVICES GUIDELINE
MANAGEMENT OF SICKLE CELL DISEASE
IN SCHOOLS**

JUNE 2019 Maryland State Department of Education

Division of Student Support, Academic Enrichment, and
Educational Policy

- 2019 – SB 600 Sickle Cell Disease Steering Committee and Services Bill. Revitalizes the Statewide Steering Committee on Services for Adults with SCD in Maryland and has potential to support services to patients
- THANK YOU!!

Many States Support SCD beyond NBS, Not Maryland

- CA - \$10,000,000
- MI - \$6,000,000
- PA - \$1,000,000
- OH - \$800,000
- **MD - \$0**

What We Need Now

- **FUNDING for SB 600 (2019)**
- **\$650,000** to fund steering committee and outreach/education efforts
- With new treatments we need to make sure access to care is in place to ensure all MD patients can take advantage of treatments **IN MARYLAND**

THANK YOU

- Special thanks to **Former Sen. Shirley Nathan-Pulliam (D) Dist. 44**; To **Del. Edith Patterson (D) Dist. 28** for sponsoring HB 1349 (2018) and HB 761 (2019) as companion bills to SB 161 (2018) and SB 600 (2019); To **Del. Joseline A. Pena-Melnyk(D) Dist. 21** for her work on HB 761 (2019).
- **We need your support to secure \$650,000 to fund SB 600.**

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